California Initiative to Advance Precision Medicine
Briefing Document

Initiative
The University of California will host California’s Initiative to Advance Precision Medicine – a collaboration of public and private academic and industry partners that will start to build the infrastructure and assemble the resources necessary to advance precision medicine-oriented data, tools and applications.

Background
Precision medicine – as envisioned in the 2011 National Academy of Sciences’ report, “Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease” i – aims to use advanced computing tools to integrate and analyze the vast amount of basic science data, together with molecular, clinical, environmental and epidemiological data on patients worldwide, so-called “big data.” The objective is to better understand diseases, with the goal of developing mechanistic insights into both rare and common illnesses, new diagnostics and therapeutics, and prevention measures. Determining the links between different types of data, and the insights that will come from them, will help scientists define why individuals respond differently to disease and therapies, develop more precise diagnostics and medications, and deliver those therapies faster and more cost-effectively to the right patient, in the right dose, at the right time. The report committee emphasized that it would take strong partnerships and collaboration to achieve the vision of precision medicine.

Our ability to navigate through integrated, complex data happens daily, yet the interface is so seamless that the vast amount of data that has been used goes unnoticed. For example, to give users the directions they’re seeking, Google Maps integrates data on road maps, construction, traffic delays, bridges, ferries and public transit routes. The goal of precision medicine is to develop a similar network that links different “layers” of information, all of the diverse data types relevant to health – from genetics and other molecular characteristics, to environmental exposures, and social factors – and grounds it with individual patients who share their data. Having this type of seamless interface for health data – something similar to Google Maps – would allow new discoveries in medicine. With such infrastructure, new data layers can be added as they become available and known to be relevant to health. There are many potential data sources from public and private partners and individuals. Once integrated, this data can be accessed and analyzed by clinicians, researchers and the public with applications that are appropriate for each group’s needs.

President Obama recently announced a national Precision Medicine Initiative in January 2015. ii The California Initiative to Advance Precision Medicine is complementary to the national effort and will bring together Precision Medicine leaders as well as collaborative projects to demonstrate the power and application of Precision Medicine, positioning California to lead in this important juncture of science, research, and medicine. The Initiative is funded through a $3 million state appropriation made in the 2014-15 budget.

Project Details
Governor’s Investment to Launch the California Initiative to Advance Precision Medicine
• $2.4 million for two demonstration projects that leverage the UC’s expansive and diverse patient data and research expertise, along with resources from public and private partners across the state. The demonstration projects will be focused on different disease areas and funding will be allocated based on project needs (not necessarily an even split). Among other criteria, a selection committee will consider the potential for tangible and immediate benefit to patients, as well as the resources that are available through partnerships with the private sector and other entities.
$600 thousand to convene public and private entities across broad disease and health-related areas, technology areas, and ethical, legal and social areas to conduct an inventory of precision medicine assets (e.g. expertise, projects, funding, infrastructure, anonymized patient data, research cohorts, etc.) across California, discuss data needs, develop ideas for safe, fair, and respectful knowledge exchange and identify priority areas for the State to contribute to the advancement of precision medicine.

**Objectives of the California Initiative to Advance Precision Medicine**

- To convene public and private entities, enabled by cutting edge technology, to foster conversation and collaboration toward advancing precision medicine;
- To create a living document with current precision medicine efforts underway in California (an asset inventory) to reduce duplication of efforts and maximize efficiency for future collaboration;
- To inform a precision medicine strategy for California based on the discussions and collaboration through the inventory process;
- To maximize private sector involvement
- To assemble expert project teams with multidisciplinary representation to conduct demonstration projects in disease focus areas;
- To share the results of the demonstration projects, particularly the platform enabling tools that are developed, with partners and the public for application in other disease areas; and
- To position California as a leader in precision medicine.

**(Initiative Rollout)**

- UC campuses will be invited to submit short proposals for demonstration projects in focused disease areas. Outreach will also be done with public and private academic and industry partners. Eligibility criteria will include leveraging medical records and expertise from across the UC system and the ability to partner effectively. Proposal and selection criteria will be communicated to the UC Chancellors and Vice Chancellors of Research in mid to late April. The criteria will also be made available on the UC Health website, along with information about how public and private partners will be able to contribute to proposals, the selected demonstration projects, and the initiative as a whole. The demonstration projects will commence in August and be completed over an 18 to 21 month period.

- UCSF will coordinate the assembly of a precision medicine asset inventory for California, detailing the key strengths and distinctive resources the State offers to advance the field of precision medicine. UCSF will collaborate with stakeholders from the public, private, non-profit and government sectors on the inventory’s development, and seek input through multiple avenues. A website for the initiative will be established at UCSF this summer and an inventory work plan will be posted on the site, with opportunities for public comment and submission of ideas. UCSF will work closely with the Governor’s Office and Office of Planning and Research to ensure the success of the initiative.

**Additional Information**

The Principal Investigator for the Initiative is Atul Butte, MD PhD, professor of Pediatrics and director of the Institute for Computational Health Sciences at UC San Francisco (UCSF). Butte is also the executive director of clinical informatics for UC Health Sciences and Services. UCSF will provide administrative leadership for the Initiative.

For media inquiries contact: Laura Kurtzman (Laura.Kurtzman@ucsf.edu or 415-476-3163)

For all other inquiries and updates about the California Initiative to Advance Precision Medicine, contact ciapm@ucsf.edu.
Frequently Asked Questions

How will the state or UC protect people's private information? What kind of information will be collected? Will anyone's private information be publically accessible?

Individual privacy and confidentiality is a top priority and highly protected. UC and partners will follow all state and federal laws concerning privacy and medical information. In addition, there will be requirements for the demonstration projects to address these issues and anticipate potential issues in this arena.

The type of information collected will vary depending on the project. The projects might not even require collecting any new information, but rather combining it differently for analysis. It could include health history, genetic information, medications used, and many other forms of data. Any research that is conducted will go through the university’s human subjects internal review board for approval and will meet the appropriate criteria for human subjects research. The state will not have access to any individual confidential information. Private information will not be available to the public.

How does Precision Medicine differ from another term called Personalized Medicine?

Personalized medicine seeks to use detailed information about patients to better interpret signs and symptoms of disease and improve diagnosis and treatment. Precision medicine doesn't focus solely on information from patients; instead, it uses advanced computing tools to collect, integrate and analyze comprehensive data across basic research and huge sets of human subjects (encompassing molecular as well as social, behavioral and population data from patients and healthy people), creating an interactive network of knowledge that would reach toward precise diagnosis and treatment decisions for each individual, while at the same time, empowering further research, advancing clinical care and informing the public at large.

Will the California Initiative to Advance Precision Medicine increase healthcare costs? What about Precision Medicine in general?

California’s initiative will not affect healthcare costs. This is a demonstration project to show the power of precision medicine and to facilitate collaboration with external partners. Whether a national precision medicine initiative would increase or decrease costs has not yet been quantitatively modeled. However, if precision medicine achieves improved prevention; precise early diagnosis; a healthier, more productive workforce; better control of chronic disease; smaller, faster and more successful clinical trials; and avoidance of unnecessary tests and ineffective therapies, it seems likely that healthcare costs would decline.

How does this initiative relate to the White House initiative? Will this be duplicative of federal efforts?

The California Initiative to Advance Precision Medicine is neither derived from nor duplicative of the White House initiative. However, it will be strongly complementary of the national effort. California’s initiative is unique. Ultimately, these investments will help to build the vast knowledge network necessary to move toward the promise of precision medicine, and they will establish a leadership role for California in the precision medicine endeavor.

Why was UC selected to receive the $3 million? Did this go through a competitive bid?

As the state’s public research university system, the University of California was selected to host the state’s initiative, which will be a collaboration of UC and other academic and private partners, through an interagency agreement with the Governor’s Office of Planning and Research. The University of California has unique expertise in this area and will be readily able to partner with external entities, whose participation will be necessary to make precision medicine
a success. The Governor’s Office and Office of Planning and Research will work closely with UC as this initiative progresses.

Why did the state choose to invest $3 million in precision medicine?

In the 2014-15 budget, the state appropriated $3 million for precision medicine. The state made this investment so that California could take the necessary steps to leverage its ample technological, scientific and medical resources and position the state as a leader in this burgeoning area of medical discovery and innovation.

What are the expected outcomes of these projects?

The anticipated outcomes include 1) a dynamic inventory of precision medicine projects in the state, so that different teams of scientists and medical researchers and technologists can connect and build on each other’s efforts; and 2) two demonstration projects focused on specific disease areas, which will provide the ability to aggregate now disparate data sets, and on which others can build applications that use data in new ways that further our understanding of disease mechanisms, enable more accurate diagnosis, improve therapies, and change clinical practice. The knowledge can then be applied to benefit whole populations.

Will this benefit primarily those who can afford to spend a lot on their healthcare? Will this initiative create more health disparities?

The California Initiative to Advance Precision Medicine is intended to provide benefits to the entire population of California and beyond. The UC system cares for a diverse patient population. In fact, some precision medicine research has specifically focused on reducing health disparities through better understanding of disease mechanisms and treatment to improve health outcomes.

How will projects or disease focus areas be selected? Will UC control the process?

UC will evaluate areas of exceptional strength within the UC system, as well as explore the potential to leverage other academic and private sector resources. A small selection committee of UC and outside experts will be responsible for selecting the disease focus areas and demonstration projects, with help from the Governor’s Office of Planning and Research, which will also assist in developing selection criteria.

Since so many people will be involved, who will own the projects?

The promise of precision medicine can only be achieved through cross-sector collaboration and the work of multidisciplinary teams. The state, its universities and private sector all play a vital role. Demonstration project ownership policies will be established that will motivate active participation, benefit project team members, and comply with patent law.

What other academic or private industry entities have expressed an interest?

UC and the Governor’s Office/Office of Planning and Research will be in discussions with a range of potential partners in the coming weeks, many of which have expressed interest or have initiated their own efforts on precision medicine.

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